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Original Communication

# Care of relatives following sudden infant death

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**Abstract**

This paper deals with 301 families who have been offered a consultation for managing bereavement following sudden infant death. Eighty-eight percent of the parents (269 families) accepted and 36 more families outwith Lower Saxony wished to be cared for. Without a previous autopsy 1.172 contacts happened from 1989 to 2003 comprising primary crisis intervention and long-term care, the latter including saying farewell before and after autopsy. One main aim was a close linking with the international self-help organization of parents (GEPS). Single cases conferences were carried out for more than five years according to the Sheffield model. There is given the methodical basis and many details of the care project.


*Keywords:* Relief from guilt; Primary crisis intervention; Long-term care

## 1. Introduction

After sudden infant death (SID), parents usually need long-term support from involved parents by the GEPS (in Germany: Common Initiative of Parents following SID). Professional assistance and self-help have to complete each other and be linked together. But, often, professional helpers are unsure concerning acute and long-term care. The Göttingen working-group 'sudden infant death' manages long-term care for parents in close cooperation with the GEPS. The target-groups of the standardized surveys had been chosen appropriately, namely professional helpers, police officers and members of the rescue service, Protestant priests, funeral directors, gynaecologists and midwives.[1–11] However, it was not possible to approach paediatricians. It must be elucidated that signals given by the professional helpers in the acute situation contribute to reduction or increase of a feeling of guilt by the parents. Another influence comes from opinions within the social sphere or contradictory information from media and other persons.[10–16]

## 2. Methodical basis

The origin of all the data are conversations for care held between 1989 and 2003 in the Institute of Legal Medicine in Göttingen with relatives of SID children. From 1989 to 2003, 301 families were contacted following SID. Eighty-eight percent of them accepted a written offer for a conversation (269 families). Among these, 36 families wished to be cared for though they did not have any previous contact – from 1989 to 2003, we had 1.172 contacts with parents overall. These were medical conversations, partly interdisciplinary ones (medical/social sciences) or based on principles of

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social sciences/family therapy. The form was the free interview. Professional helpers were also interviewed about their knowledge and procedures with the acute and late phase of SID. There can be differentiated four constellations:

### 2.1. Primary crisis approach

During primary crisis intervention in the majority of cases, the emergency physician is replaced in the domestic area, but more rarely in regional hospitals, by an emergency pastor. At an early stage, the self-help organization of parents (GEPS) is contacted.

### 2.2. Follow-on meetings

A second meeting with the parents can include saying farewell to the child. Following an introductory medical conversation the next of kin are accompanied to the farewell-room. After the forensic scientist has withdrawn quietly, the parents are given as much time as they need. Afterwards, the conversation may be continued.

### 2.3. Subjects of conversation

The time schedule of the third contact is particularly extensive due to an interdisciplinary conversation (doctor who carried out the autopsy/social or family therapist). Before discussing details, a basis is created by exoneration of the parents from guilt by the forensic pathologist, often by answering questions about SID. The chronicological structure of the conversation deals with family incidence of SID, pregnancy, birth, development, possible illnesses of the child, mode of sleeping, breast-feeding and nutrition, conspicuous events and strains, course of the day before and constellation of the day of death as, e.g. scene of death, emergency help, assignment of professional rescue, service by the police, funeral sorrow and resources. The parents usually put questions though there is an internal structure, but later on the conversation is lead by the family therapist. Nevertheless, parents often wish that their experiences should be used as indirect help for other parents. Prior to the meeting, parents receive documents by the self-help organization (GEPS). They bring along pregnancy records and medical notes. Other documents provided by obstetricians and paediatricians are analysed together with results of the post-mortem. In Berlin and during the first five years of the Göttingen period (1989–2003), all findings were discussed by specialists in single-case conferences and only after this had happened the final diagnosis of SID or non-SID was made.

### 2.4. Long-term care

The fourth phase is represented by long-term care based on preceding conversations. Long-term care means to be open to further conversations with parents and keep contact with them (family therapist) as long as required. Most of the contacts end when any further children are one year old. The time of pregnancy with a considerable increase of the anxiety level often results in repeated intense requirements for advice by the family therapist.

## 3. Structure of the working-group 'sudden infant death' in Göttingen and that of the offer of help following SID

The long-term company created in Göttingen is based on the former team in Berlin with structures according to the format of Sheffield. Single-case conferences were an obligatory part of the procedure supported by paediatric medical notes from. Most of the paediatricians in Berlin could be won over a participation on the conferences, maybe because invitations were sent by the Federal Bureau of Health (BGA, now called Robert-Koch-Institute), whereas, in Göttingen, only 19% accepted single-case conferences. From the beginning of the 90 s, we continued our investigations without neuropathological examinations which had really been considered to be indispensable,[14,17–22] because the results could not be included in the conversation with the parents. Long-term care and primary crisis intervention are realised in close collaboration with the GEPS. During single-case conferences medical files are compared with information obtained from the conversation (e.g. concerning familiar diseases, pregnancy and birth, infantile development and diseases, stress-factors, death-scene, resuscitation, investigations and given help). Information was provided prior to the single-conferences, partly directly after autopsy so that the parents were informed by letter about the cause of death being SID, including details for an appointment.

It is helpful for the parents to receive the results of the examination as soon as possible, even if histological, neuropathological, bacteriological, virological, mycological, toxicological and environmental analytical investigations are still due. Only in a few cases did the diagnosis of SID have to be corrected later on because of secondary investigations as, e.g. to myocarditis. However, it is very difficult to clarify such an amendment to the parents.

## 4. Structure and contents of care conversation

In Berlin, the care procedure was finished by a detailed discussion (forensic pathologist, social scientist and paediatrician in charge) prior to a final conversation with the parents after the single-case conference. In Göttingen, conversations were held in a mixed gender type by the forensic pathologist (male) and a family therapist (female social scientist). This change came about because it is a hindrance to long-term care when only men are involved in conversations. The mixed approach in the sense of a cross-over test led to a new quality. Parents found it especially important to have an early conversation. However, the primary conversation should not be held immediately following the autopsy,[23] because parents are unable to grasp at the time. Also, well meant information about time and place of a

post-mortem represents massive stress. Frequently, they went to the hospital where the post-mortem was carried out. Pictures of the postmortem were clearly in front of their eyes during the time of waiting.

During the subsequent conversation with the pathologist who had carried out the autopsy, the parents were totally paralysed. Although first contacts by telephone were definitely appropriate to relieve from guilt by the "authority" of the pathologist himself, it seems to be better to hold the first conversation after the child's funeral has taken place. This primary conversation takes 2–2½ hours, but a planned funeral might represent an extreme situation closing any sensoric access. Intake of psychotropic drugs on occasion of the funeral is a rather common obstacle, being an extensive conversation. It is always commenced by a message given in the first person intending relief from the feeling of guilt. A trustful basis requires that any unjustified fear of the parents that their child had suffocated, is rejected from the very beginning.

Taking part in this conversation is never easy for parents. Many of them reported on their fear of this idea, which could possibly confirm that their child had died from suffocation. Such fears may extend so far, that a mother reproaches herself for having killed her child. This may result from an acute archaic reaction or due to post-traumatic stress syndrome with severe depressions. This reaction is often due to an escape of blood from the upper respiratory tract. That is why – from a medico-legal point of view[23,24] – for all those parents care is an urgent matter if traces of blood are present around mouth and/or nose, on sheet, pillow and clothes. This may also occur when the child is lifted in a moment of desperation. Blood spots have a maximum signal effect and can be misunderstood to be due to suffocation or even severe resuscitation trauma.[25] For the parents their thoughts on death from asphyxia is so fixed that another explanation is accepted only after having hesitated for a long time. It has to be clarified that blood stains are external signs of haemorrhagic pulmonary oedema. This is pathognomic for SID and only due to prone position. Lividity may exacerbate the effect. Special scenes of death as, e.g. with face position or covered position increase the fear of unnoticed suffocation.[26]

Early signals from professional helpers and the police may support the parents in their wrong sight and self-reproaches, due to wrong interpretations. This problem requires a close collaboration between forensic pathology and police.[11,14] Many parents describe pictures of the death-scene having burnt into them, so that they were unable to recall previous pictures of their child for almost six months. The (female) family therapist has an equal part within the conversation and discussion about help and sorrow. Continuation of the contact is offered and accepted in almost all the cases being held at home with the parents present in familiar vicinity. The company is continued as long as the parents wish to, at least until the next child has reached its first birthday. In single cases, care may last up to five years and even longer.

## 5. A further pregnancy

Usually in the first meeting parents think of a further pregnancy in an ambivalent way. Many even considered a type of psychogenic infertility following SID[27]; but, usually, a new pregnancy is thought to have a neutral or positive effect on bereavement. However, an increase of the fear level is significant.[4,8,28] An analysis of 787 conversations during long-term company involving 115 families following SID, revealed that 90 mothers were pregnant again when their child died due to SID.[29] Almost 60% of them became pregnant within six months after SID. Partly, an offer of care was accepted only during a further pregnancy, what might indicate a high potential of restlessness and fear. It was particularly burdening if medical examinations during pregnancy did not deal with the dead child or non-acceptance of the sorrow within the social community.

## 6. Primary crisis intervention in case of SID

Primary crisis intervention by a forensic pathologist is unusual, but might be justifiable today as a special way with regard to emergency spiritual welfare. The beginning of crisis intervention with SID in Göttingen was in 1989. Prior to this, an emergency spiritual welfare throughout Germany was set up. However, emergency spiritual welfare and teams for crisis intervention of aid organizations operate with full-time employees, whereas medico-legal crisis intervention represents a commitment of a university institute.

Alarm in cases of SID is not given by the police headquarters but by the fire brigade. The emergency pastor is informed the same way the Church offers emergency spiritual welfare independent of gender, denomination or religion. An emergency pastor does not only fill the gap after the emergency doctor has left until the relatives arrive, but may offset the relatives with their fear during resuscitation. The pastor acts as messenger and mediator because relatives sometimes have to leave the room when resuscitation, investigations or removal of the body is done. Contacts with the rescue team can be used to give information as, e.g. "They are doing everything for your child, but I don't know whether they will succeed." Furthermore, the emergency pastor can open the door or leave it open for the parents.[30] After reporting death he/she accepts the parents with their personal and non foreseeable manner of sorrow.

## 7. The role of the forensic pathologist

The forensic pathologist has to be introduced to the parents by the emergency physician so as to be in a position to solve problems of the acute situation. It is essential for the relatives to recognize that the forensic scientist attends on their behalf only. In this situation parents are defenceless. It is ethically unjustifiable to leave parents in the dark about any research interest or to press them morally to collaborate in this acute situation.

The role of the forensic pathologist also includes mediation as permission by the parents is necessary for each examination of the child. However, multiple experiences make clear that both sides appreciate medical mediation because the situation may become more and more incomprehensible on arrival of the police. Being confused, parents tend to ask themselves about reproaches for the death of their child by police investigations. Unknown persons have access to the child. This is exacerbated by the silent question of the parents, whether their child has possibly been suffocated. The parents are given back part of their autonomy which had been taken away by the emergency situation. This is realised by obtaining permission for autopsy whilst giving the appropriate respect. From experience, parents rarely reject a request to approach their child made by helpers or the forensic pathologist. They are keen to know what has happened and what are the next steps.

## 8. Saying farewell

Parents should always be encouraged to say goodbye to their child, because the mother is often not allowed or able to pick up her child after she is informed about death. Resuscitation and police investigations may lead to a separation between parents and child, being a frequent reason for intense resistance against the idea of repeated exposition to the horrible impression of the deceased child. Without help, an approach of the parents to their child to say farewell is possible only in a few cases.[31] However, it is known from conversations how much parents suffer later on from the fact they did not say farewell to their child.

A medico-legal examination, often revealing massive facial lividity, can help to encourage parents to say farewell, e.g. by changing the child's position. Sometimes, emergency doctors show lack of assurance concerning forbidden changes with respect to following investigations that, when certifying death, they do not even turn over the child. Due to a flat dorsal position after turning the child over, livor mortis can be really concise in the face. Therefore, a half-slanted dorsal position with a higher position of the head is recommended to accelerate draining lividity. After discrete control of the situation, the parents should be informed that they can now say farewell to their child due to the changes (''There are no longer red stains in the face. Your child looks like being asleep'').

Parents are frequently unsure whether siblings should say farewell or not. It could be elucidated that a reliable support of them breaks away due to an exclusion of their parents in a highly dramatical situation.[32] Their parents are helpless and forced to be passive after the death of their baby, who had recently been the centre of the family. For bereavement return of autonomy represents a central issue. Therefore, parents and siblings of all ages should be encouraged to say farewell. Self-reproaches may be the reason that parents burden themselves because they did not say farewell to their child. Therefore, the mother should also be encouraged in the sense of mild paternalism again and again to say farewell.

The first principle for saying farewell is that there will be no primary crisis intervention or care in case of smallest external lesions or other injuries. Care and examinations at the scene of death must be separated clearly. Parents and investigational departments have a right of clarity. The second principle requires attention to be given to 'blood stains' by putting it down to haemorrhagic pulmonary oedema. Both, helpers and relatives are afraid of talking about such findings. Blood spots are ignored whereas thinking is linked to it and means that the cause of death was suffocation.

## 9. Fear, self-reproach and autopsy

Help from the forensic pathologist is characterized by the fact that blood escaping from mouth and nose is directly mentioned to explain its probable cause and to point out that this finding is quite common. It must also be elucidated that further examinations have to be carried out to give information about the next steps to the parents.

The single steps of care are developed from questions of the mother, based on medical aspects. Formally, the conversation is always held in a sitting position on the same level for all participants. A question regularly put is to seek clarification whether further examinations include a postmortem. An answer allows one to give the hint that parents organized in the GEPS expect a reliable statement on the cause of death by a postmortem. Although conversation is used as means for information to recover autonomy, parents are burdened by the only imagination of a post-mortem. Intense refusals result from religious and cultural relationships. But also parents who wish an autopsy with an offer for care ask themselves repeatedly whether their decision was right.

Parents should be able to say farewell prior to, or after, autopsy. They are welcomed by the pathologist whom the parents had contacted before and who carried out the postmortem or will do so. Firstly, the parents are offered a conversation which is usually very short. After this, the pathologist accompanies them to their laid out child, lights a candle and then withdraws from the room. Parents are able to stay with their child as long as they want to. If they wish they can continue the conversation with the pathologist afterwards.

## 10. Body contact with the dead child

Primary crisis intervention has to offer definite medical ways to help the mother. Maybe, she wants to change her child's clothes, which are possibly damaged or altered due to resuscitation; or, put on the most beautiful things. She will easily succeed in undressing, but have difficulties in putting on fresh clothes due to rigor mortis. Intense scruples may hinder the mother to overcome the rigor mortis because she fears to breaking her child's arms. So she

appreciates help with dressing her child. Based on preceding examinations of the child by himself, the forensic pathologist knows about intensity of the rigor mortis. Mostly, it is sufficient enough to bend the arms carefully with two fingers.

Furthermore, breast-feeding should be discussed due to continuing milk production. Therefore, the mother is asked by the forensic pathologist whether she needs something to wean. Her request for help can wilfully be passed to the police who take the prescription for a prolactin inhibitor and get a pump within the acute situation from the closest pharmacy. This help by the police is more expressive than all other explanations in the sense of practical help and relief from guilt.

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## References

1. Beal SM. Some epidemiological factors about sudden infant death syndrome (SIDS) in South Australia. In: Tildon J T, Roeder L M, Steinschneider A, editors. *Sudden infant death syndrome*. New York: Academic Press; 1983. p. 15–28.
2. Dyregrov A. Parental reactions to the loss of an infant child: a review. *Scand J Psychol* 1990;**31**:266–80.
3. Dyregrov A, Mitchell JT, Hordvik E. When a child dies: helping the helpers. In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 280–8.
4. Dyregrov A, Matthiesen SB. Anxiety and vulnerability in parents following the death of an infant. *Scand J Psychol* 1995;**28**:16–25.
5. Helweg-Larsen K, Brockenhus Schack A. How to deal with the media. In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 297–9.
6. Jørgensen J-K. Fair and constructive use of the media in the SIDS context. In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 293–6.
7. Quirke S, Kiberd D, O'Doibhilin M, Lynch E. Care for SIDS families: a coordinated approach. In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 277–9.
8. Vance J C, Najman J M, Thearle M J, Embelton G, Boyle F M, Lutvey C. Long-term outcome of SIDS families: a longitudinal study including comparisons with other forms of infant loss. In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 273–6.
9. Zagdanski D. The pain of losing a child: a personal account. In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 300–3.
10. Helmerichs J. Farewell and primary measures. On the influence of primary measures by the resuscitation team and the police on the bereavement reaction and its coping in the family. In: Saternus KS, Klostermann P, editors. *Sudden infant death. Care for parents. Research in Legal Medicine*, Vol. 3. Lübeck: Schmidt-Römhild; 1992. p. 57–63.
11. Saternus KS. Primary measures and reactions of parents, the professional rescue service, and the police with sudden infant death. In: Saternus KS, Klostermann P, editors. *Sudden infant death. Care for parents. Research in legal medicine*, Vol. 3. Lübeck: Schmidt-Römhild; 1992. p. 71–103.
12. Helmerichs J, Saternus KS. Psychological care for parents and siblings after sudden infant death. In: Bengel J, editor. *Psychology in ambulance service and emergency medicine*. Berlin: Springer; 2000. p. 137–46.
13. Kastner-Voigt M. Consultation of parents affected by SID concerning the following pregnancy and family therapeutical aspects. In: Helmerichs J, Saternus KS, editors. *The pregnancy following SID. Research in legal medicine*, Vol. 11. Lübeck: Schmidt-Römhild; 1995. p. 61–73.
14. Rognum TO, Lier LA. Police investigation and SIDS: an improved system of cooperation between health personnel, forensic, pathologists and the police? In: Rognum TO, editor. *Sudden infant death syndrome. New trends in the nineties*. Oslo: Scandinavian University Press; 1995. p. 289–92.
15. Vance JC, Foster WJ, Najman JM, Embelton G, Thearle MJ, Hodgen FM. Early parental responses to sudden infant death, stillbirth or neonatal death. *Med J Aust* 1991;**155**:292–7.
16. Videka-Sherman L. Coping with the death of a child. A study overtime. *Am J Orthopsychiat* 1982;**52**:688–98.
17. Becker LE. Neuropathological basis for respiratory dysfunction in sudden infant death syndrome. In: Tildon JT, Roeder LM, Steinschneider A, editors. *Sudden infant death syndrome*. New York: Academic Press; 1983. p. 99–114.
18. Becker LE, Takashima S. Chronic hypoventilation and development of brain stem gliosis. *Neuropediatrics* 1985;**16**:19–23.
19. Kinney HC, Burger PC, Harrell Jr FE, Hudson Jr RP. "Reactive gliosis" in the medulla oblongata of victims of the sudden infant death syndrome. *Pediatrics* 1983;**72**:181–7.
20. Naeje RL. Brain-stem and adrenal abnormities in the sudden-infant-death-syndrome. *Am J Clin Path* 1976;**66**:526–30.
21. Oehmichen M, Theuerkauf I, Bajanowski T, Merz H, Meissner M. Enhanced reactivity of Alz-50 antibody in brains of sudden infant death syndrome victims vs. brains lethal hypoxic/ischemic injury. *Acta Neuropathol* 1998;**95**:280–3.
22. Takashima S, Armstrong D, Becker L, Bryan C. Cerebral hypoperfusion in the sudden infant death syndrome? Brainstem gliosis and vasculature. *Ann Neurol* 1978;**4**:257–62.
23. Saternus KS, Helmerichs J, Kastner-Voigt M. Care for families following SID – an interdisciplinary task. In: Oehmichen M, editor. *Sudden infant death. Subjects of paediatry*, Vol. 6. Lübeck: Hansisches Verlagskontor; 1993. p. 98–109.
24. Saternus KS, Thiel A, Kastner-Voigt M. "I've killed my child." Experiences with grave depression among mothers from the point of view of psychiatry and forensic medicine following a sudden infant death. *Nervenarzt* 1998;**69**:53–8.
25. Saternus KS, Helmerichs J, Walter-Humke S. Sudden infant death (SID). Part 1: limits of resuscitation. Part 2: tasks of care in emergency medicine. *Der Notarzt* 1996;**12**(8–11):43–6.
26. Kleemann WJ, Urban R, Eidam J, Wiechmann B, Tröger HD. The scene of death in cases of SID. *Rechtsmed* 1991;**1**:147–51.
27. Mandell F, Wolfe LC. Sudden infant death syndrome and subsequent pregnancy. *Pediatrics* 1975;**56**:774–6.
28. Lewis SN. Material anxiety following bereavement by cot death and emotional security of subsequent infants. *Ch Psychiat Human Dev* 1983;**14**:55–61.
29. Helmerichs J, Saternus KS. Psychosocial care during a subsequent pregnancy after sudden infant death (SID). Results of a long-term study on 115 families. *Z Geburtsh Neonatal* 2000;**204**:99–105.
30. Meyer W. About the dealing with death during work on the emergency doctor's car. *Der Notarzt* 1985;**1**:99–103.
31. Saternus KS. How to say farewell in cases of sudden infant death. *Z Med Ethik* 1999;**45**:45–50.
32. Klostermann P. Meeting with siblings after sudden infant death. In: Saternus KS, Klostermann P, editors. *Sudden infant death. Care for parents. Research in Legal medicine*, Vol. 3. Lübeck: Schmidt- Römhild; 1992. p. 105–14.